MEDICAL ETHICS AND TRUTH TELLING IN THE CASE OF ANDROGEN INSENSITIVITY SYNDROME

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In Brief • En bref

Should a physician always tell the truth to a patient? Is biomedical ethics too "politically correct" in certain situations? The second-place winner in the 1995 Logie Medical Ethics Essay Contest discusses whether telling the truth is the proper course for a physician dealing with certain patients.

Un médecin doit-il toujours dire la vérité à un patient? L'éthique biomédicale comporte-t-elle trop de «rectitude politique» dans certaines situations? Dans le deuxième texte primé au Concours Logie de dissertation en éthique médicale, l'auteur demande s'il convient pour un médecin de dire la vérité à certains patients.

The Dr. William Logie Medical Ethics Essay Contest is open to undergraduate medical students studying at Canadian universities. The contest, named in honour of Canada's first medical graduate, is sponsored by CMAJ. *The following essay won the $750 second prize in the 1995 competition.*

My first year of medical school included an opportunity to observe patient management by a variety of physicians in clinical settings, and a course in biomedical ethics. An ethical issue of special interest to me was truth telling by physicians and, more specifically, the circumstances under which a physician may withhold information from a patient regarding a medical diagnosis.

Generally, most health care professionals I observed in my first year agreed that they do not always disclose all details of a diagnosis to a patient, because to do so would take too much time and might be too confusing. Today, however, people are demanding more time with their physicians. We are also in the midst of an information explosion that has given patients access to quick facts about an assortment of medical topics. Time constraints and the element of confusion are no longer considered the appropriate reasons they once were for withholding facts from a patient, but what rules apply when there is a need to protect patients from potential emotional harm?

During my first year in medicine I learned about a peculiar endocrine disorder called androgen insensitivity syndrome (AIS). Providing details about this problem to patients demands a great deal of discretion on the part of the attending physician and raises this question: Should the physician withhold particular details from these patients? I want to apply the general ethical issue of truth telling to a specific case of AIS.

THE DISORDER

Which information ought to be transmitted in medical relationships? Answers will depend in part on ethical norms. Is the objective to produce the most happiness, protect individual rights or follow general moral rules, such as the prohibition against lying?[1]

AIS is a congenital disorder in which a genetic male lacks the receptors necessary for the masculinizing effects of male hormones. As a result, these genetic males grow up to look exactly like adult females. Patients with this disorder seek medical advice mainly because they lack menstrual periods and experience pain during sexual intercourse due to a short, underdeveloped vagina. Testing will show that the patient has the XY chromosome pattern of genetic males and internalized testes, but no ovaries.[2] In short, these genetic males lead the lifestyles of normal females but they do not menstruate and cannot bear children. AIS does not worsen with time, but it cannot be corrected. The only services the physician can provide are surgical reconstruction of the vagina and counselling on adoption.

I will refer to AIS patients as females, since they display both the physical and psychologic characteristics of females. My argument will be restricted to situations in which the patient is completely comfortable with her female sexuality before a diagnosis of AIS is made. Finally, I will stress that an AIS patient who has undergone reconstructive surgery leads the same lifestyle as a heterosexual, infertile, genetic female.

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Within the boundaries of these distinctions, I believe that physicians who treat AIS patients are justified in not disclosing the information that the patient is genetically male.

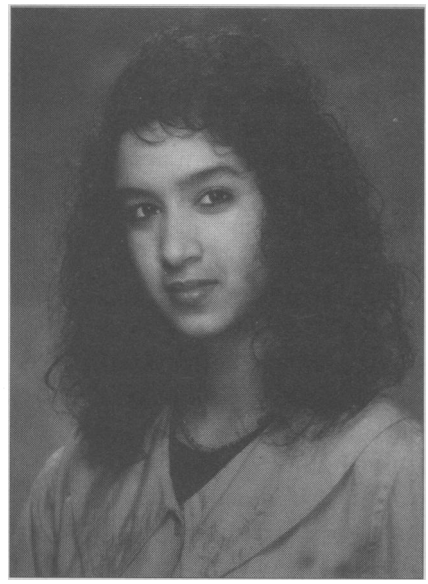
The alternative argument

The issue of truth telling in the case of AIS can be addressed with reference to the deontological theory developed by Immanuel Kant, who argued that there is a "categorical imperative" and this is the principle from which our various moral duties derive. The imperative tells us that in all our actions we should never treat persons merely as a means, but always as ends in themselves.[3] This Kantian framework provides a basis for the moral value accorded to individual autonomy.

There are three senses of autonomy: autonomy as liberty of action, autonomy as freedom of choice and autonomy as effective deliberation.[3] In the case of AIS, the third sense is most relevant. Truly autonomous people can deliberate effectively only if they have the abilities required for effective reasoning and the disposition to exercise them. In the biomedical context, physicians can constrain their patients' decision-making processes by deliberately withholding information; therefore, a physician who lies to the AIS patient is not providing the details necessary for her, as a rational moral agent, to prepare for her future. As a result, the physician undermines the patient's ability to deliberate effectively, as well as her ability to be fully autonomous.

According to the categorical imperative, we all have perfect and imperfect moral duties. Perfect duties require us to do or abstain from certain acts, and there are no legitimate exceptions to them. A transgression in this category of duty occurs whenever one person treats another merely as a means. Perfect duties include the responsibility to keep promises, not to kill an innocent person and not to lie. Our imperfect duties require us to promote personal perfection and the welfare and happiness of others.

However, actions taken in the name of these goals must never be at the expense of a perfect duty.[3] Since every person has a perfect duty to others not to lie, it is a straightforward implication of Kantian deontology that a physician should not lie to an AIS patient, even if telling the truth would reduce her happiness or welfare, and thus violate an imperfect duty.



Anita Natarajan

For these reasons, lying violates the formulation of the categorical imperative that requires us to treat people not merely as a means, but as ends in themselves. Therefore, on Kantian grounds, lying is not morally justified.

The counterargument

The above argument is deductive but unsound because the premise that claims to provide strong support for the conclusion that "lying is morally wrong" is not necessarily true.

Kant would argue that lying to the patient undermines her autonomy. This is understood to mean that her present autonomy is affected. But what about her future autonomy? A fully autonomous person is characterized as one who is capable of, among other things, making rational decisions. In one sense, people are rational when they are capable of choosing the best means to some chosen end. One's rationality, and thus autonomy, can be diminished by internal factors such as strong emotions.[3] Most AIS patients approach their physicians with complaints of lack of menstruation (and thus infertility) and painful sexual intercourse. With respect to such complaints, the patient's chosen ends are to find a solution to the problem of infertility and to be free of pain. The physician can provide her with the best means to these ends: counselling regarding adoption, and reconstructive surgery.

Given the nature of AIS, there can be no better means to the chosen end, even if the patient is given information about her genetic sex. Her future autonomy is protected because she and her husband or partner can continue their physical and emotional relationship without the influence of potential insecurity about her sexual identity. The patient will be offered options such as adoption, which will enable her to lead the same lifestyle as any other infertile genetic female.

On the other hand, the AIS patient who is told she is genetically male is likely to experience confusion or strong emotions that could diminish her sense of rationality, her ability to deliberate effectively and, in effect, her future autonomy. The physician who withholds information about a patient's genetic sex undermines her present autonomy in order to respect her future autonomy. In the case of AIS, future autonomy is more important.

The second argument concerns Kant's view that people, including physicians, can never evade their perfect duty not to lie. I maintain that physicians who withhold information

from AIS patients are not actually lying: they are only deceiving. The physician is justified in telling the patient that she is infertile and that reconstructive surgery of the vagina may alleviate her pain — these statements are not lies. Webster's Third New International Dictionary defines *lie* this way: "to convey an untruth, to make an assertion of something known or believed by the speaker to be untrue."[4] Therefore, failure to tell the patient that she is actually a genetic male with pathology in the androgen receptors is not a lie.

That the patient still believes she is genetically female implies that deception has occurred. In response to the second argument, we do not have a perfect duty not to deceive. Physicians do not even have an imperfect duty not to deceive, because not deceiving the patient does not promote welfare or happiness. Physicians who withhold information from patients are deceiving them, not lying to them, and therefore they do not violate their moral obligation to abide by their perfect and imperfect duties.[5]

The defence

Although the argument using Kantian deontology is in favour of truth telling, W.D. Ross's deontologic theory of *prima facie* duties supports physicians who withhold information. Unlike Kant, Ross maintains that there are no absolute or unconditional duties, only *prima facie* duties that have no unitary basis comparable to the categorical imperative. Rather, they emerge out of our numerous "morally significant relations," such as those between physicians and patients. Our *prima facie* duties include fidelity, beneficence and nonmaleficence.

The morally significant relationship between physicians and patients requires physicians, by virtue of their duties of fidelity, to tell patients the truth. They also have duties of beneficence and nonmaleficence that require them to act in the best medical interests of the patient and to not cause harm. Since neither is unconditional, the latter two duties may override the former as the physician may consider them more important. Physicians who tell patients with AIS that they are genetically male adhere to their duty of fidelity, but I think the lack of positive consequences and the potential negative consequences are sufficient reason for violating the duty of fidelity.

The fact the patient has the XY chromosome pattern appears to be more of academic than physiologic importance to the AIS female who is diagnosed as infertile. On the one hand, there is no alternative course of action she can take because this disorder cannot be corrected. On the other hand, a heterosexual AIS female who is satisfied with her current sexuality may suffer from confusion or a loss of dignity when informed that she is genetically male. This may affect not only her, but also her husband or partner. I believe it would be cruel to disclose this finding to the patient, since it would not enable her to make any decisions that would improve her life in any possible way. In fact, it could produce unnecessary and devastating emotional and psychologic effects that will impede her chances of leading a normal life.

Although Kant's argument is systematic and orderly, it is heavily rule based. It thus fails to provide exceptions to perfect duties and does not recognize the subtleties that underlie the dealings between physician and patient. There is no rationale for the possible infliction of unnecessary emotional pain simply to abide by a rule that does not cater to the special needs of different patients.

Applying the ethical issue of truth telling to a specific medical condition narrows the boundaries within which a methodical argument can be made. More importantly, it illustrates that biomedical ethics is subject to situational variables that are difficult to incorporate into a generalized directive for physicians.

As a second-year medical student, I find medical ethics to be too "politically correct." In the name of maintaining nobility and respect within the medical profession, there is tremendous pressure on ethicists, politicians and health care professionals alike to formulate a code of ethics that sounds politically correct. The nonspecific directive to "never deceive a patient" indeed may appear to be just and noble on the surface, but in the case of AIS it is not the best course of action.

Law and philosophy serve as effective guides for patient management, but the physician must ultimately rely on his or her own judgement, taking the facts and values of the individual case into account. Physicians' sensitivity, empathy, integrity and clinical expertise should merge to give them a firm sense of what constitutes effective treatment and patient satisfaction.

This is a necessary route to follow to good ethical conduct, and thus it is good medical conduct.

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